

COLD FEET IN CHILDREN WITH NEUROLOGICAL DISORDERS

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To all the children, parents and assistants
who made this work possible

TABLE OF CONTENTS

ABSTRACT.....	1
LIST OF PUBLICATIONS.....	2
ABBREVIATIONS	3
INTRODUCTION	5
Background	5
Skin temperature.....	5
Skin temperature and central nervous system disorders	6
Acupuncture	6
Definition and classification of cerebral palsy	7
Accompanying impairments in cerebral palsy	8
Care-giving for a child with complex disorders.....	8
Community services support.....	8
Framework and rational for this thesis.....	9
OBJECTIVES	10
METHODS	11
Design and study participants	11
Intervention (Study I)	15
Measures.....	16
Statistical analysis	18
RESULTS	21
Study I.	21
Study II.	23
Study III.....	24
Study IV.....	27
DISCUSSION	31
Skin temperature.....	31
Skin temperature and central nervous system disorders	31
Skin temperature and sympathetic activity	32
Accompanying impairments and symptoms in CP	33
Accompanying symptoms and sympathetic activity.....	34
Treatment.....	35
Parental mood and health	37
Parental daily living experiences.....	37
Community services support and parental responsibility	38
METHODOLOGICAL CONSIDERATIONS	39
Sample size.....	39
Skin temperature measurement	39
Self-constructed questionnaire	39
Proxy report.....	40
Gross motor function.....	40

IMPLICATIONS AND FUTURE DIRECTIONS	41
CONCLUDING REMARKS.....	43
APPENDIX. Questionnaire	44
ACKNOWLEDGEMENTS.....	59
REFERENCES	61

Table of tables

Table 1. Overview of study design and subjects for Studies I–IV.....	11
Table 2. Characteristics of the children, and needle position and mode of stimulation during acupuncture treatment	16
Table 3. Statistical methods used in studies I-IV	18
Table 4. Basal skin temperature in hands and feet before the first acupuncture series	21
Table 5. Differences in mean skin temperature between non-walking children with cerebral disorders and healthy controls; estimate and 95% confidence intervals ...	23
Table 6. Distribution of accompanying impairments and specific symptoms in walking and non-walking children with CP	25

Table of figures

Figure 1. Raytec Raynger ST2L	16
Figure 2. Treatment effects on skin temperature compared to baseline.....	22
Figure 3. Proportion of parental anxiousness for walking and non-walking children’s (a) physical and (b) psychological health and numbers of symptoms and impairments of the children by frequency of parental anxiousness	28
Figure 4. Numbers of parents with affected health by frequency of anxiousness for their walking and non-walking children’s (a) physical and (b) psychological health	29

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ABSTRACT

These studies focused on presence of cold feet in children with neurological disorders and raised the questions: Does acupuncture affect skin temperature? Are cold feet a general symptom in children with neurological disorders? Are cold feet associated with other symptoms? What are the moods, health, and daily life experiences of these children's parents?

Study I assessed effects of acupuncture on skin temperature in children with neurological disorders. The study was of pilot character, to determine if further investigation in a larger, well-characterised group could be worthwhile.

Study II analysed skin temperature variation between preschool children with and without neurological disorders to determine if skin temperature and walking ability were correlated.

Study III investigated accompanying symptoms, such as cold extremities, constipation, pain, sleeping disorders, and well-being, and their treatment to determine (i) whether cold extremities is a general problem, (ii) what symptom treatment the children had received, (iii) associations between cold extremities and gross-motor function, and (iv) associations between cold extremities and other symptoms borne by the child.

Study IV described moods, health, and daily life experiences of the children's parents to investigate (i) impact that the child's impairments and symptoms have on the family and (ii) community services support.

Study I (single subject design; each child was its own control) comprised 6 children with neurological disorders. Study II (hypothesis refinement study) comprised 25 healthy children recruited from a community preschool and 15 children with cerebral or spinal cord disorders from Child and youth neurohabilitation in Örensköldsvik. Studies III and IV (postal survey, descriptive hypothesis-generating studies) comprised 107 children with cerebral palsy (Study III) and parents of 106 of these (Study IV) from 8 habilitation centres in the northern region of Sweden.

Conclusions:

- Acupuncture may increase skin temperature in some children with neurological disorders and cold extremities.
- Non-walking children with cerebral damage had significantly lower mean hand and foot skin temperature compared to healthy controls.
- Of the 5 symptoms – cold extremities, pain, sleeping disorders, constipation, and impaired well-being – (i) most of the children with CP had had 1 or several symptoms for more than 1 year and (ii) symptom frequency was generally higher in non-walking children than in walkers. Of the children who had had symptoms for more than 1 year, a surprisingly large number had received no treatment for them.
- Care-giving for a child with CP may affect parents' moods, health, and daily living – especially if the child has several impairments and symptoms. Frequent parental anxiousness regarding the child's physical and psychological health might be associated with affected parental health.

Key words: Skin temperature/Acupuncture/Autonomic dysfunction/Cerebral palsy/Spinal cord disorders/Pain/Constipation/Sleeping disorders/Well-being/ Parental health/Parental mood/Restricted time/Services support

LIST OF PUBLICATIONS

This thesis is based on these publications, which are referred to by their Roman numerals.

- I. Svedberg LE, Nordahl G, Lundeberg T. (2001) **Effects of acupuncture on skin temperature in children with neurological disorders and cold feet: an exploratory study.** *Complementary Therapies in Medicine* 9: 89-97.
- II. Svedberg LE, Stener-Victorin E, Nordahl G, Lundeberg T. (2005) **Skin temperature in the extremities of healthy and neurologically impaired children.** *European Journal of Paediatric Neurology* 9(5):347-54.
- III. Svedberg LE, Englund E, Malker H, Stener-Victorin E. (2007) **Parental perception of cold extremities and other accompanying symptoms in children with cerebral palsy.** *European Journal of Paediatric Neurology* 12(2): 89-96.
- IV. Svedberg LE, Englund E, Malker H, Stener-Victorin E. (2009) **Comparison of impact on mood, health, and daily living experiences of primary caregivers of walking and non-walking children with cerebral palsy and provided community services support.** *European Journal of Paediatric neurology* Jul 21 [Epub ahead of print] PMID:19628416

ABBREVIATIONS

BFMF	Bimanual Fine Motor Function Scale
BMI	Body Mass Index
CCK	Cholecystokinin
CGRP	Calcitonin gene-related peptide
CHQ	Child Health Questionnaire
CI	Confidence interval
CP	Cerebral palsy
EA	Electro-acupuncture
GMFCS	Gross Motor Functional Classification System
HSL	Public Health Act
HRV	Heart rate variability
LASS	Assistance Benefit Act
LSS	Support and Services for Persons with Certain Functional Impairments
MACS	Manual Ability Classification System
PEG	Percutaneous endoscopic gastrostomy
SD	Standard deviation
SLO	Smith-Lemli-Opitz syndrome
SoL	Social Services Act
SP	Substance P
SPSS	Statistical Package for Social Sciences
TENS	Transcutaneous electrical nerve stimulation
VCIG	Variational cardointervalography
WHO	World Health Organization

INTRODUCTION

Background

Little emphasis has been attributed to peripheral skin temperature dysfunction in children with neurological disorders,^{1,2} although thermal dysfunction and thermal regulation of the skin were investigated in adult patients and healthy people.³⁻⁶ Other disabilities might have overshadowed thermal dysfunction in children with neurological disorders, but thermal dysfunction is a parental concern, and our clinical impression is that extremities – especially the feet, in child patients– are frequently cold when they are indoors and outdoors. Because the children are seldom capable of expressing how subnormal temperature affects them, there is risk of misinterpretation and/or lack of concern. Available treatments, such as massage and heating elements in socks, rarely work satisfactorily.

Skin temperature

Skin temperature is generally stated to be around 32°C,⁷ although normal skin temperature values in children and adults are undetermined. Two sympathetic effector organs mainly regulate skin temperature locally: the cutaneous blood vessels and the sweat glands under the control of the central nervous system.⁸ The thermoregulatory centre of the central nervous system is located in hypothalamus. The efferent vasomotor and sudomotor pathways (projecting to the cutaneous blood vessels and sweat glands, respectively) originate in the hypothalamus, descend to the mesencephalon, pons and posterolateral medulla oblongata, and transmit to the preganglionic neurons in the intermediolateral column of the thoraco-lumbar spinal cord. Preganglionic neurons synapse in the paravertebral ganglia with the postganglionic neurons innervate cutaneous blood vessels and sweat glands. The sympathetic supply of the skin is spatially organized, for example, sympathetic postganglionic neurons that supply upper extremities are found in the stellate ganglion, and the cell bodies that innervate the legs are located in the lower lumbar paravertebral ganglia.⁸ The postganglionic vasoconstrictor fibres in the skin of hands and feet are adrenergic, and the chemical mediator (noradrenaline) released by the sympathetic nerve impulses act on the peripheral excitatory or alpha receptor sites of the vascular smooth muscles of arteries and arterioles, causing vasoconstriction.^{8,9} A correlation was also found between skin temperature and circulation, where room temperature is constant, which indicates that skin temperature change corresponds to vasodilation alteration.^{10,11}

Skin temperature and central nervous system disorders

Coldness in the affected extremity of stroke patients was reported as an unpleasant symptom that affects their quality of life.^{3,4} The severity of the problem varied considerably, but most patients were constantly aware of the symptom and obtained only limited relief from local warming.³ Findings of unpleasant coldness in the extremities of stroke patients have been brought to the attention of clinicians who treat these patients.³ So it could also be important for clinicians who work with children with central nervous system disorders.

Acupuncture

Acupuncture is a potent mode of sensory stimulation whereby needles are inserted into the skin and deeper tissues, which results in afferent activity in peripheral nerves. The needles are stimulated by manual rotation to evoke a needle sensation (*Qi*), which results in feelings of heaviness, numbness, and warmth in the region of needle insertion. Electro stimulation of needles, i.e., electro-acupuncture (EA) is another mode of stimulation. Low frequency (1-4 Hz) EA, with intensity high enough to evoke twitches in the muscles, probably excites receptors in the muscles (ergoreceptors), which are activated during muscle contractions.¹² Physiological counterparts to processes activated by electrical or manual stimulation can be seen in physical exercise.¹³

One of many reasons for the influence of sensory stimulation on vascular effects lies in the innervation of the cutaneous vascular bed by sympathetic neurons in the autonomic system.⁸ Acupuncture is one mode of sensory stimulation that has a strong vasodilatory effect.¹⁴⁻¹⁸

Circulation is regulated by stimulation of A δ - and C-fibres, i.e., type III and IV afferents, which having a modulatory link to sympathetic outflow. At the end of a session of sensory stimulation, skin temperature is increased as sympathetic activity is reduced. This effect is probably due to several varying mechanisms.

First, sensory stimulation directly influences sympathetic reflexes at spinal levels. Second, sensory stimulation activates supraspinal reflexes that opioids at least partially mediate, because large doses of naloxone can eliminate effects.¹⁹ Influence of the hypothalamus β -endorphin system is probably significant, because lesions counteract effects in this structure. Sensory stimulation also causes antidromic activation with a local release of substance P (SP) and a calcitonin gene-related peptide (CGRP) – both of which are strong vasodilators.^{20,21} Release of endogenous opioids, especially β -endorphin, is also a key factor in pain control.¹³

Subjectively observed skin-temperature increases have been noticed when children with dystonic CP and painful muscle spasm were treated with acupuncture,²² and skin-temperature increases on hands – immediately after acupuncture sessions – were found in children with neurological disorders.²³

Definition and classification of cerebral palsy

Cerebral palsy (CP) is a well-recognized neurodevelopmental condition to all clinicians who work with children with neurological disorders. About 2–3 in 1000 children in the developed world have CP.²⁴ It comprises a group of conditions that are heterogenous in cause and manifestations. Many authors – such as Little,²⁵ Gowers,²⁶ and Mutch²⁷ – have tried to describe and classify CP over the years. After an International Workshop on Definition and Classification of Cerebral palsy held in Bethesda, Maryland (US) in 2004, the participants put forward a revised definition and classification. They emphasised the motor disorders of CP and recognised other developmental disorders of performance and behaviour that can and often do accompany it. Subsequently, an updated definition was announced:²⁸

Cerebral palsy (CP) describes a group of disorders of the development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behaviour, and/or by a seizure disorder.

The classification is aligned with the recently proposed definition and classification of CP.²⁸ It includes the concept of unilateral and bilateral spastic cerebral palsy, and it recommends classifying by the dominant type of tone or movement abnormality, categorized as spasticity, dystonia or ataxia.

The functional consequences of involvement of the upper and lower extremities should be separately classified using objective functional scales. The Manual Ability Classification System (MACS)²⁹ or the Bimanual Fine Motor Function Scale (BFMF)³⁰ assess upper extremity function. For the key function of ambulation, the Gross-motor functional Classification System (GMFCS) groups individuals with CP into one of five levels – based on functional mobility or activity limitation.³¹ Children in level I have the most independent motor function and children in level V have the least. The validity and reliability of the GMFCS were found to be good when professionals used it with children aged 2-12.³² Agreement between family reports and professional classifications has also been found to be excellent, which suggests that family reports of the GMFCS are a

reliable method for measuring gross-motor functional abilities of children aged 6–12.³³ The GMFCS has recently been extended and revised, and the GMFCS-E&R now includes an age band from 2 to 18 yrs.³⁴

Accompanying impairments in cerebral palsy

As per the definition of CP, many children may have accompanying impairments that may override motor impairments in some children. Several studies on children with CP illustrated correlations between motor severity and other aspects of neurodevelopmental impairment such as epilepsy, mental retardation, and sensory impairments.^{30,35-37} Other studies reported that pain³⁸ and sleeping disorders³⁹ are common in children with CP.

Care-giving for a child with complex disorders

Caring for a child with complex disabilities has sometimes proved (1) to be detrimental to the physical health and the psychological well-being of parents of children with chronic disabilities and (2) to have an impact on family income and family functioning.⁴⁰ As per the World Health Organization (WHO): “Health is a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity”.⁴¹

Quality of life has a restricted meaning close to the WHO definition of health. Quality of life usually means health-related quality of life and refers to some aspects of functional status such as physical/occupational function, psychological state, social interactions, and somatic discomfort.⁴² When people refer to health status, they generally consider broader medical and functional well-being that is sometimes reported in terms of “impact of disability”.⁴³

Community services support

Satisfaction with social support and family function in families with children, who have chronic disabilities, are associated with lower parent burden and better parent well-being.⁴⁰ To provide good living conditions for persons with considerable and permanent functional impairments, Sweden’s law on Support and Service for Persons with Certain Functional Impairments (LSS) sets out special rights.⁴⁴ The LSS supplements other legislation such as the Social Services Act (SoL) and the Public Health Act (HSL). Ten measures, such as personal assistance for help in daily living and short stays away from the home, are free of charge. This law applies to three groups, namely, persons with:

1. Intellectual disability, autism, or a condition resembling autism
2. Significant, permanent intellectual impairment after brain damage in adulthood due to an external force or a physical illness

3. Other major, permanent physical or mental impairments that are clearly not due to normal ageing and that cause considerable difficulties in daily living and consequently, extensive need of support and services.⁴⁴

As per the intellectual status definition, a child with CP might qualify for group 1 or 3 and might be considered eligible for assistance under LSS.

Framework and rational for this thesis

Every single disorder linked to motor impairment increases the total impairment of the child. So it is crucial to identify accompanying symptoms, which might be possible to treat. But effective, long-lasting treatments against cold feet are lacking. Acupuncture is one mode of sensory stimulation that has a strong vasodilatory effect, and studies have indicated that skin temperature change corresponds to vasodilation alteration. So an exploratory study was set up to investigate possible acupuncture effects on skin temperature.

Knowledge of peripheral skin temperature dysfunction in children with neurological disorders is very scarce. For example, are cold feet a general symptom in children with neurological disorders? An objective assessment of skin temperatures in children with and without neurological disorders was thus of interest.

It is also unknown if cold feet are associated with the child's walking ability or other symptoms borne by the child. Investigating the children's impairments and varying symptoms was thus important.

Caring for a child with complex disabilities, while going through the motions of daily family life, might create challenges for parents. So it was critical to expand knowledge of parents' situations when the children were surveyed.

OBJECTIVES

The overall aims of this thesis are to increase knowledge of peripheral skin temperature dysfunction in children with neurological disorders, to explore possible treatment methods, and to elucidate factors that might have an impact on the children and their parents. The specific aims of the four studies were to:

1. Assess effects of acupuncture on skin temperature in children with neurological disorders (Study I).
2. Investigate skin temperature differences between preschool children with and without neurological disorders (Study II).
3. Explain if any correlation existed between skin temperature and the children's walking ability (Study II).
4. Describe accompanying symptoms – such as cold extremities, constipation, pain, sleeping disorders and well-being – in children with CP and investigate treatments the children had received for these symptoms (Study III).
5. Investigate if cold extremities is a general problem in children with CP, and analyse and discuss associations between cold extremities and gross-motor function and between cold extremities and other symptoms (Study III).
6. Describe mood, health and daily life experiences of the children's parents and explain the impact children's impairments and symptoms may have on the parents (Study IV).
7. Investigate community services support for the families (Study IV).

METHODS

Design and study participants

Table 1 presents an overview of study design and subjects for Studies I–IV.

Table 1. Overview of study design and subjects for Studies I–IV

Study	Design	Subjects
I	Single subject. The study was of pilot character and assessed effects of acupuncture on skin temperature.	Six children and youth (age range 4–16, 5 girls and 1 boy) with neurological disorders. Four had CP, one progressive encephalopathia, and 1 SLO.
II	Hypothesis refinement. This study assessed skin temperature variation to determine whether skin temperature and walking ability were correlated.	40 preschool children. 15 (age range 2–7, 47% girls) had cerebral or spinal cord disorders. 25 (age range 1–5, 40% girls) had no neurological disorders.
III	Descriptive, hypothesis-generating. A postal survey study on presence of cold extremities and other associated symptoms, and their treatment, to determine (i) whether cold extremities is a general problem, (ii) what symptom treatment the child had received, (iii) associations between cold extremities and gross-motor function, and (iv) associations between cold extremities and other symptoms borne by the child.	107 children (age range 5–16, 60 boys and 47 girls) with CP.
IV	Descriptive, hypothesis-generating. A postal survey study on parental mood, health, and daily life experiences to investigate (i) impact that the child's impairments and symptoms have on the family and (ii) community services support.	Parents of 106 children in study III; 64 were parents of walkers 44 were parents of non-walkers

CP = cerebral palsy, SLO = Smith-Lemli-Opitz syndrome

Methods

Study I. A study of pilot character that assessed affects of acupuncture on skin temperature.

Design: Single subject

Subjects: Six children and youth with neurological disorders

Based on the parents' concern for their children's cold feet and after consultation with a senior child neurologist, 5 girls and 1 boy with neurological disorders were selected from Child and youth neurohabilitation in Örnköldsvik, Sweden. Parents signed informed-consent forms after they received verbal information on possible acupuncture mechanisms and effects. The parents and the children's personal assistants, who had not experienced acupuncture before, were introduced to the sensation of needling in the forearm. It was important that the person who would accompany the child during the acupuncture sessions was calm and able to give the child an opportunity to feel secure.

Six children and youth aged 4–16 yrs (5 girls and 1 boy) participated. One child had progressive encephalopathia, 1 child had Smith-Lemli-Opitz syndrome, and 4 children had CP. Per the recently proposed classification for CP,²⁸ the children with CP would be diagnosed as follows: 3 children had bilateral spastic CP (diplegia and tetraplegia) and 1 child had dyskinetic CP. All 6 children had learning disabilities and similar gross-motor functional levels; gross-motor function of the children with CP was level V.

Study II. A hypothesis refinement study that assessed skin temperature differences to determine whether skin temperature and walking ability were correlated.

Design: Hypothesis refinement

Subjects: Twenty-five healthy preschool children and 15 preschool children with neurological disorders

In study I, the parents of the 6 children with neurological disorders had a subjective impression that their child's feet were cold. Skin temperature measurements before acupuncture also showed that the children's mean skin temperature was below what is considered normal skin temperature, i.e., 32°C.⁷ But it was unknown if this is a general symptom in children with neurological disorders. So Study II measured skin temperature in children with and without neurological disorders.

In Örnköldsvik, Sweden, recruitment letters describing the study and its purpose were (i) mailed to the parents of all 17 preschool children with cerebral or spinal cord disorders at Child and youth neurohabilitation and (ii) distributed by

Methods

teachers at a community preschool to parents of 36 healthy children. Oral parental consent was given for 15 children with neurological disorders and written parental consent for 31 healthy children to participate in the study. Six healthy children withdrew, so the final group comprised 15 children with neurological disorders (89%; aged 2–7 yrs; mean age 4 yrs and 6 mos, SD 19 mos; 47% girls) and 25 children (69%; aged 1–5 yrs; mean age 3 yrs and 6 mos, SD 14 mos; 40% girls) with no signs of any central or peripheral nervous system disease.

Of the 15 children with neurological disorders, 11 had cerebral disorders and 4 had spinal cord disorders. Ten of the children with cerebral disorders were diagnosed with CP; 5 were walkers and 5 non-walkers. Per the proposed classification for CP,²⁸ 3 walkers had unilateral spastic CP (hemiplegia) at level I, 1 walker had bilateral spastic CP (diplegia) at level II, and 1 walker had bilateral spastic CP (diplegia) at level III. Of the 5 non-walking children, 4 had bilateral spastic CP (2 with diplegia classified at level IV, 1 with diplegia at level V, and 1 with tetraplegia at level V) and 1 had dyskinetic CP at level V.

The child with ischemic cerebral damages in the occipital region and no CP diagnosis walked without aids but needed to hold the handrail when going up or down the stairs due to mild balance disturbances. Of the 4 children with spinal cord disorders, 3 were non-walkers and 1 child walked on its own without walking aids in all surroundings.

The director of Child and youth neurohabilitation, the principal and vice principal of the preschool, and the ethics committee at Umeå University, Umeå, Sweden approved the study.

Study III. A postal survey study on presence of cold extremities and other associated symptoms, and their treatment, to determine (i) whether cold extremities is a general problem, (ii) what symptom treatment the child had received, (iii) associations between cold extremities and gross-motor function, and (iv) associations between cold extremities and other symptoms borne by the child.

Design: Descriptive, hypothesis-generating

Subjects: 107 children with CP

In study II, non-walking children with cerebral disorders had lower hand and foot skin temperature than children without neurological disorders. So Study III investigated children with CP. A proxy report was chosen so that all children between 5 and 16 yrs could participate, including children with learning disabilities and poor communication skills.

Methods

Children and families at habilitation units are protected by professional confidentiality and may not be contacted directly for research purposes. So, the questionnaire was sent to the parents by their habilitation unit with an introduction letter and a prepaid envelope addressed to the unit. If the caregivers of a child were separated, both were sent the survey with a special introduction letter, which explained that both parents were being asked to participate in the survey. One reminder was sent to those who had not answered after 2 wks. The returned envelopes were forwarded unopened to the first author.

The study comprised 161 children with CP, 5–16 yrs, enrolled at 8 of 10 child and youth habilitation centres in the northern region of Sweden. Two centres were excluded because they had recently been involved in another survey organised by other researchers. Information about 110 of 161 (68%) children was received. Three children were excluded: 1 child had an inappropriate diagnosis, 1 was outside the study age group, and information on gross-motor functioning was missing for 1 child. The final group comprised 107 children (67%), 60 boys and 47 girls, mean age 11 yrs 8 mos (SD 2 yrs 11 mos). The ethics committee at Umeå University, Umeå, Sweden approved the study.

Study IV. A postal survey study on parental mood, health, and daily life experiences to investigate (i) impact that the child's impairments and symptoms have on the family and (ii) community services support.

Design: Descriptive, hypothesis-generating

Subjects: Parents of 106 children and youth with CP

Study IV comprised the parents of 107 children in study III. One family, whose child was living in a student home most of the time, was excluded. Three children had 2 respondents each because their caregivers were separated. The parents of one of these children had identical answers. The final group comprised 108 parents.

One adult (11 fathers and 67 mothers) in 78 families and both adults in 30 families responded to the questionnaire. Sixty-four were parents of walkers and 44 of non-walkers. The children's functional ability was classified using the Gross Motor Function Classification System (GMFCS).³¹ Walkers were classified as GMFCS I-III and non-walkers as GMFCS IV-V. Data on missing families were unavailable due to confidentiality. The ethics committee at Umeå University, Umeå, Sweden approved the study.

Intervention (Study I)

Acupuncture test sessions

Each child attended 4 test sessions – 1 session per wk for 4 wks – to determine the best points and mode of stimulation for affecting skin temperature in the feet. The first 3 test sessions were randomised. At each of these, acupuncture needles were inserted in GV 20 (the crown of the head) and one of these combinations:

- The legs at GB 4 and BL 60, points that are segmentally related to the somatovisceral innervation of sympathetic nerves regulating peripheral blood flow^{45,46}
- The arms at TE 5 and LI 11, points that evoke general sympathetic responses⁴⁷
- A combination of legs and arms at GB 4, BL 60, TE 5, and LI 11

At the fourth session, the child was needled at the points that had produced the greatest effect on foot temperature during the first 3 test sessions.

In the first 3 sessions, needles were manually stimulated 3 times during a 20-min period. Acupuncture point stimulation evoked a resistance to the needle that is similar to the local response patients experience as *Qi*.⁴⁸ In the fourth test session, the needles were attached to an IC-1107 stimulator (Wilkris & Co AB, Stockholm, Sweden) and electrically stimulated, electro-acupuncture (EA). The stimulator supplied low-frequency 2 Hz EA with biphasic pulses and a pulse width of 0.1-ms. The intensity was adjusted between 2–5-mA to achieve non-painful local muscle contractions, thereby modulating sympathetic nervous system activity.⁴⁹ For practical reasons, 4 children were seated and 2 were prone during the sessions.

The first series of acupuncture treatments

After the test sessions, each child received 8 (1 child, 7) sessions of acupuncture treatments – 2 per wk for 4 wks – comprising the points that had produced the greatest foot temperature increase for the child (Table 2). Needles were stimulated during a 20-min period.

Leg points GB 4 and BL 60 were stimulated by low-frequency EA in 3 children and manually in 1 child. Arm points TE 5 and LI 11 were needled manually in 1 child. And 1 child received a combination of electrical stimulation of the 2 leg points and manual stimulation of the 2 arm points.

Methods

Table 2. Characteristics of the children, and needle position and mode of stimulation during acupuncture treatment

Child	Age	Sex	Disorder	Gross motor function	Acupuncture treatment	
					Needle position	Mode of stimulation
I	4	Girl	Dyskenetic CP	GMFCS, level V	Legs	EA
II	16	Girl	Bilateral spastic CP (tetraplegia)	GMFCS, level V	Legs + arms	EA legs+ manual arms
III	11	Boy	Progressive encephalopathia	Non-walker	Legs	EA legs+
IV	5	Girl	Bilateral spastic CP (diplegia)	GMFCS, level V	Arms	Manual
V	4	Girl	Smith-Lemli-Opitz syndrome	Non-walker	Legs	EA
VI	15	Girl	Biateral spastic CP (diplegia)	GMFCS, level V	Legs	Manual

EA = electro-acupuncture; GMFCS = Gross Motor Function Classification System

Second series of acupuncture treatments

To assess cumulative effects and verify parental reports of major subjective improvement at the first series of treatments, the children were offered a second treatment series 1 year later. One child withdrew due to family circumstances, another due to lowered general condition, and a third had moved out of the area. So 3 children underwent the second series of treatments. Choice of points and mode of stimulation were similar to what the child had received in the first series, during 20-min sessions twice a wk for 4 wks. Each child received 5 to 8 sessions.

Measures

Skin temperature measurements (Studies I and II)

In Studies I and II, skin temperature was measured with a handheld non-contact IR thermometer (Raytec Raynger ST2L; Raytek Inc., Santa Cruz, CA, USA; see Figure 1.



Figure 1. Raytec Raynger ST2L

The instrument converts infrared radiation to Celsius degrees (response time 500 msec, accuracy $\pm 2\%$ and repeatability $\pm 1\%$ of reading). Before skin temperature measurements were begun, the Medical Device Department at Örnköldsvik Hospital calibrated the IR thermometer. Because the distance between the surface being measured and the thermometer determines the size of the spot being measured, a wooden stick was used to fix the distance. The stick was attached to the sighting groove of the instrument and projected 3 cm in front of the recessed lens.

In study I, skin temperature was assessed at these acupuncture points or sites: PC 8 (the palm), the midpoint of the third metacarpal bone (the dorsal surface of the hand), KI 1 (the foot sole), ST 36 (the dorsal surface of the foot), and at 2 reference points (1 cm above EX 2 on the forehead and on the suprasternal fossa).

Before the first acupuncture test session, initial skin temperature was measured 5 times at 5-min intervals on 2 occasions – once a wk for 2 wks. During the series of test sessions, skin temperature was measured before and immediately after each acupuncture session. During the first treatment series, skin temperature was measured before and after each acupuncture session and at the 1-mo follow-up.

Before the second treatment series, 1 year after the first, skin temperature was measured 3 times at 15-min intervals on 4 occasions – twice a wk for 2 wks. During the treatment series, skin temperature was measured before and immediately after each acupuncture session; at the 1- and 3-mo follow-ups (3 times at 15-min intervals on 4 occasions – twice a wk for 2 wks); and to capture any delay in temperature increase following acupuncture, on 1 or 2 treatment-free days each wk (three times at 15-min intervals).

In study II, hand and foot skin temperature was measured on 1 occasion, 3 times at 15-min intervals, at the same measuring points used in study I.

Self-constructed questionnaire (Studies III and IV)

The questionnaire focussed on children with CP (study III) and their parents (study IV), and contained open-ended and closed-ended questions. In study III, the questionnaire covered these topics: (i) gross-motor functional ability, (ii) accompanying neurological impairments, (iii) general medical background, (iv) the child's condition and present treatment regarding skin temperature, pain, sleep, and constipation, (v) well-being, and (vi) general health. In study IV, the questions investigated (i) family characteristics, (ii) parental mood, health and daily living experiences and (iii) community services support. The questions were based on clinical knowledge and experience, literature in similar areas,⁵⁰⁻⁵⁵ and personal communications with paediatric researchers. The instrument was pre-tested on 2

colleagues and 3 parents of children with neurological disorders (non-participants) and then revised as needed.

Statistical analysis

Table 3 presents an overview of the statistical methods used in this thesis. Study I analyses were made with version 8.1 and Study II analyses with version 9.1 of SAS. Study III analyses were made descriptively with version 14.0, and Study IV analyses with version 15.0 of the Statistical Package for Social Sciences (SPSS; SPSS Inc, Chicago, IL, USA). Study III and IV graphic illustrations were made with Origin (version 7.5; OriginLab Inc., Northampton, MA).

Table 3. Statistical methods used in Studies I-IV

Statistical method	Studies			
	I	II	III	IV
<i>Descriptive statistics</i>				
Mean (min, max)	x	x		
Mean (CI)	x			
Mean (SD)		x		x
Proportion of subjects (%)			x	x
<i>Analytical statistics</i>				
Paired student t-test	x			
Linear regression	x			
Pearson's product moment correlation		x		
Linear mixed model		x		
Spearman correlation			x	

Descriptive statistics

Mean values, mins and maxs, standard deviations (SD), and confidence intervals (CI) were calculated for various group characteristics – such as skin temperature and age – of the various study populations. Percentage distributions of number of children and parents described non-parametric data.

In studies III and IV, 3 of the children had 2 respondents each because their caregivers were separated. The parents of one of these children gave identical answers. When parental responses for the other 2 children differed, answers from each parent were weighted by 0.5, which caused decimal frequencies in the results.

A limit of 2 SD for body mass index (BMI) analyses was chosen to detect over- and underweight children.⁵⁶

For some analyses in studies III and IV, the 5 ordered response choices (*yes, every day; yes, every week; yes, every month; yes, a few times/year; and no, never*)

were clustered into new categories. To analyse distribution of specific symptoms by gross-motor function level (study III), the 5 response options were clustered into 2 groups: *yes* or *no*. To describe the frequency of specific symptoms (study III) and the frequency of parental anxiousness (study IV), the 5 response options were clustered into 3 groups: *a few times/week or more*; *a few times/month or less*; and *no, never*.

To describe frequency of restricted time and daily living interference during the last month (study IV), the 4 ordered response choices *yes, every day*; *yes, a few times/week*; *yes, only at occasional times*; and *no, never* were clustered into 3 groups for data analysis: *a few times/week or more*; *occasionally*; and *no, never*.

In study IV, the description of the impact of the child's impairments and specific symptoms on the family was based on 2 parental groups, parents with walking and with non-walking children, respectively, because several studies on children with CP have illustrated correlations between the child's motor severity and other aspects of neurodevelopmental impairment and symptoms.^{30,35-37}

Analytical statistics

Skin temperature changes following acupuncture. In study I, student's *t*-test analysed differences between before- and after-session measurements to determine if any significant momentary temperature changes occurred in any body region.⁵⁷ Temperature differences were analyzed (separately for each child and body part) as a simple random sample from a normally distributed population of differences, generated under the same circumstances.⁵⁸ Bonferroni's method was used to control for the overall Type I error rate.⁵⁹

During the first acupuncture series, changes in basal skin temperature and in acupuncture effect – due to repeat sessions – were estimated after each treatment using linear regression with temperature as the *y* variable and time as the *x* variable.⁶⁰

To assess cumulative effects (first and second acupuncture series), differences in skin temperature were calculated relative to the first baseline at selected time points. A regression model estimated cumulative effects.⁶⁰ The Dunnett method adjusted for multiple comparisons;⁵⁹ 95% confidence limits are presented for mean levels.

Skin temperature differences between body parts and groups of children. In Study II, Pearson's product moment correlation coefficient calculated the association between left- and right-side temperature at the 4 measurement points.⁵⁷ A linear mixed model⁶¹ evaluated possible differences in mean skin temperature between subgroups and measurement point:

$$\text{temp} = \text{age} + \text{sex} + \text{group} + \text{measurement point} + \text{group} \times \text{measurement point} + \text{subject} + \varepsilon$$

Methods

Sex was treated as a fixed factor with 2 levels (*girl* and *boy*) and measurement point as a fixed factor with 4 levels (*hand dorsal*, *hand palm*, *foot dorsal*, and *foot sole*). As could be seen, the correlation between the left and right side of each measurement point was very high, so nothing would have been gained by separating the left and right sides (8 instead of 4 levels) of the 4 points in the modelling process.

Group was also treated as a fixed factor with 4 levels: *healthy control*, *cerebral damage: non-walker*, *cerebral damage: walker*, and *spinal cord disorder*. Since there was only 1 walker in the last group, it was not statistically meaningful to divide the group into walkers and non-walkers. The subject variable was treated as a random factor with 40 levels (the 40 children), and age was fitted as a covariate. During the modelling process, variation in skin temperature between non-walkers was bigger than between walkers (including the healthy controls). So it was necessary when fitting the model to allow residual variances, ε , for these 2 groups.

Accompanying specific symptoms in children with CP. Spearman's correlation coefficient calculated the correlation between presence of cold extremities and other specific symptoms in study III⁵⁷ using each of the 5 answer options for occurrence and frequency of a specific symptom (*yes, every day*; *yes, every week*; *yes, every month*; *yes, a few times/year*; and *no, never*). Bonferroni's method adjusted for multiple comparisons in the correlation analysis.⁵⁹

RESULTS

This section summarises results of each article; only some data are shown. All data and results are described in detail in the individual articles.

Study I.

Effects of acupuncture on skin temperature in children with neurological disorders

Skin temperature

Skin temperature measurements before the start of acupuncture treatment showed that the children's mean skin temperature on the feet was below the stated normal skin temperature of 32°C⁷ (Table 4).

Table 4. Basal skin temperature in hands and feet before the first acupuncture series

Child	Forehead			Suprasternal fossa		
	mean	min	max	mean	min	max
I	33.7	32	35	36.7	36	37
II	35.9	35	36	no observations		
III	34.4	33	36	36.0	35	37
IV	34.2	33	36	34.8	34	36
V	34.6	34	36	35.7	35	36
VI	36.2	36	37	35.9	35	37

Child	Hand dorsal						Hand palm					
	left			right			left			right		
	mean	min	max	mean	min	max	mean	min	max	mean	min	max
I	28.1	26	31	27.5	24	32	28.5	26	30	29.1	26	32
II	31.9	30	34	31.5	30	33	33.2	32	35	31.2	30	32
III	28.6	26	32	27.8	26	30	29.8	27	33	28.7	26	32
IV	27.8	26	29	28.8	27	31	27.7	24	29	27.2	25	29
IV	26.6	26	27	26.7	26	27	27.1	26	29	27.6	26	30
VI	23.6	22	25	23.2	22	25	22.4	22	23	22.5	21	24

Child	Foot dorsal						Foot sole					
	left			right			left			right		
	mean	min	max	mean	min	max	mean	min	max	mean	min	max
I	23.5	22	26	23.8	22	26	22.8	21	25	22.9	22	24
II	25.8	24	27	25.1	23	27	25.1	23	27	24.6	23	26
III	25.4	24	28	24.3	24	26	24.8	23	27	23.7	23	24
IV	27.3	25	30	27.8	26	30	27.0	25	29	27.1	26	29
V	26.5	26	27	26.7	26	27	26.8	26	27	26.6	26	27
VI	21.4	21	23	21.7	21	22	19.6	19	21	19.3	19	20

Effects of acupuncture on skin temperature

The evaluation indicated that acupuncture may increase skin temperature in the extremities, both momentary and over time. Onset, level, and site of increase varied among the children. Momentary skin temperature increase, immediately after each acupuncture session, was mainly seen in the hands of 3 children. A tendency toward a cumulative effect in improved skin temperature occurred in the hands and feet of 2 of the 3 children who attended supplementary acupuncture sessions.

During the second acupuncture series, the child with progressive brain disease experienced an extended temperature rise with persistent temperature increase at the 1- and 3-mo follow-ups. Post-sessional temperatures increased above the stated normal skin temperature of 32°C ⁷ in hands and towards 32°C in feet. Figure 2 illustrates treatment effects on skin temperature of the right-hand palm (solid line) and the right-foot sole (dotted line) in this child.

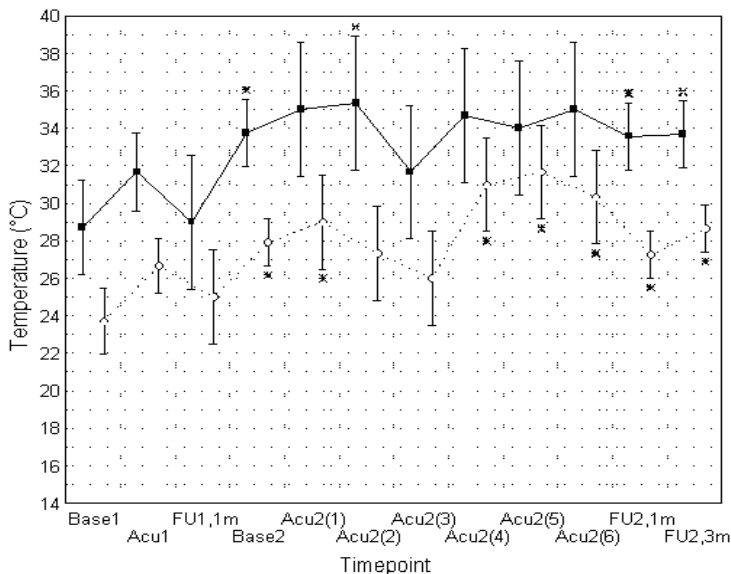


Figure 2. Treatment effects on skin temperature compared to baseline

In the child with spastic diplegia, treatment effects after the second series were cumulative with temperature increases in the hands of about 4°C at the 1-mo follow-up. But temperatures did not reach 32°C .⁷ The child with Smith-Lemli-Opitz syndrome had no benefit from acupuncture.

Comments: The parents' subjective impression that their children's feet were cold was verified by skin temperature measurements. A possibility of extended effects

Results

on skin-temperature increases was seen after supplementary acupuncture sessions. Onset, level, and site of increase varied among the children.

Study II.

Skin temperature in the extremities of children with and without neurological disorders

Skin temperature

A strong positive correlation in skin temperature was seen between the left and right hands and between the left and right feet in all children – healthy and with neurological disorders. Skin temperature was generally lower in the feet than in the hands.

Skin temperature differences between groups of children

Mean hand and foot skin temperature was significantly lower in non-walking children with cerebral damage compared to healthy controls (Table 5). Among children with cerebral damage, mean foot skin temperature was significantly lower in non-walkers than in walkers.

Table 5. Differences in mean skin temperature between non-walking children with cerebral disorders and healthy controls; estimate and 95% confidence intervals

	Mean skin temperature		Difference	95% CI	p-value
	Cerebral disorders non-walkers	Healthy controls			
Hand dorsal	30.4	31.9	-1.4	(-2.7 , -0.1)	0.0320
Hand palm	30.9	33.5	-2.6	(-3.9 , -1.3)	0.0002
Foot dorsal	26.9	30.7	-3.8	(-5.1 , -2.5)	< 0.0001
Foot sole	25.8	28.6	-2.7	(-4.0 , -1.4)	< 0.0001

Cold extremities were not found in children with spinal cord disorders. No difference was noted in the hands between healthy controls and these children. But mean skin temperature on the feet was significantly higher in children with spinal cord disorders than in healthy controls.

No significant association between skin temperature and age or sex was found.

Comments: Lower skin temperatures, in both hands and feet, may be present in non-walking children with cerebral disorders compared to healthy children.

Study III.

Parental perceptions of cold extremities and other accompanying symptoms in children with CP

Gross-motor function and muscle tonus

Gross-motor function was classified as GMFCS level I in 37% (40/107) of the children, as level II in 19% (20/107), as level III in 4% (4/107), as level IV in 21% (23/107), and as level V in 19% (20/107). The 107 children were divided into two, gross-motor-functional groups: 60% (64/107) were classified as walkers (GMFCS I–III) and 40% (43/107) as non-walkers (GMFCS IV–V). Spasticity was reported in 77% (80.5/105) of the children and dystonia in 37% (37/99.5).

General medical background

Forty-five percent (48/107) of the children were born at full term (>36 gestation wks), 17% (18/107) between wks 32 and 36, 15% (16/107) between wks 28 and 31, and 17% (18/107) before wk 28. Gestation period was unknown in 7% (7/107). BMI analyses of 81 children yielded that 22% (18/81) were underweight, 64% (52/81) normal weight, and 14% (11/81) overweight.

Of the 107 children, impairment in oral-motor function reflected by difficulties with food and liquid intake was present in 19% (20/107) and 16% (17/106), respectively. Severe problems – percutaneous endoscopic gastrostomy (PEG) feeding and gastro-oesophageal reflux – were reported in 11% (12/107) and 13% (14/106), respectively. These feeding problems occurred mainly in non-walking children. Incontinence occurred in 25% (26.5/107) of the children.

Accompanying neurological impairments and symptoms

A larger proportion of non-walking children than of walking children was reported to have accompanying neurological impairments, cold extremities, pain, sleeping disorders, constipation, and impaired well-being (Table 6).

Results

Table 6. Distribution of accompanying impairments and specific symptoms in walking and non-walking children with CP

	Walkers GMFCS I-III (n = 64) n (%)	Non-walkers GMFCS IV-V (n = 43) n (%)	Total (n = 107) n (%)
Impairments:			
Learning disability	15 (23%)	25 (60%) ^b	40 (38%) ^d
Speech disorders	15 (23%)	32 (74%)	47 (44%)
Visual impairments	23.5 (37%)	36 (84%)	59.5 (56%)
Hearing impairment	3 (5%)	2 (5%) ^b	5 (5%) ^d
Epilepsy	14 (22%) ^a	23 (54%)	37 (35%) ^d
Specific symptoms:			
Cold extremities	36 (56%)	40 (93%)	76 (71%)
Pain	31 (48%)	34 (79%)	65 (61%)
Sleeping disorders	23 (36%)	31 (72%)	54 (51%)
Constipation	14 (22%)	31 (72%)	45 (42%)
Impaired well-being	31 (48%)	26.5 (64%) ^c	57.5 (55%) ^e

^a n = 63 ^b n = 42 ^c n = 41.5 ^d n = 106 ^e n = 105.5

Cold extremities

Parents reported that 71% (76/107) of the children had cold extremities: 8% (6/76) only had cold hands, 24% (18/76) only cold feet, and 68% (52/76) cold hands and feet. Ninety-seven percent (74/76) of these children had had the symptom more than 1 year; 78% (59/76) had cold extremities at both normal and low room and outside temperatures and 22% (17/76) only at low outside temperatures. Forty-four percent (33/75) had told their parents about their cold extremities in words or by other means, and 56% (42/75) had not. In the parents' opinion, possible causes for cold extremities were low blood circulation, impaired motor ability, and spasticity.

Pain

Pain was observed in 61% (65/107) of the children, and 94% (61/65) of these had experienced pain for more than 1 year. The parental opinion was that pain, for example, was located in the muscles and joints or due to constipation.

Sleeping disorders

Disturbed sleep – such as delayed insomnia, disrupted sleep, early awake, or a combination of these – was reported in 51% (54/107) of the children, and 93% (50/54) of these children had had the disorder more than 1 year. Suggested causes of the child's sleeping problems were difficulty to relax and calm down or presence of spasticity, anxiety, epilepsy, and pain.

Constipation

Forty-two percent (45/107) of the children were reported to have constipation, and all 45 had had the symptom more than 1 year. Parental opinions of possible causes for this problem were impaired motor ability, poor liquid intake, and intake of pureed food.

Impaired well-being

Well-being was thought to be impaired in 55% (57.5/105.5) of the children. This had been observed for more than 1 year in 91% (50.5/55.5) of these children. Suggested causes were impairments and spasticity.

Association between cold extremities and other symptoms

An association between cold extremities and sleeping disorders ($r = 0.43$, $p < 0.001$), constipation ($r = 0.41$, $p < 0.001$), pain ($r = 0.33$, $p < 0.01$), and impaired well-being ($r = 0.32$, $p < 0.01$) was observed. No association was found between cold extremities and spasticity, epilepsy, gestation age, birth weight, or BMI, even though the proportion of children with cold extremities, who were underweight (27%; 16/59), was higher than the proportion of underweight children with no cold extremities (9%; 2/22). An association between cold extremities and sleeping disorders ($r = 0.45$, $p < 0.01$) and pain ($r = 0.45$, $p < 0.01$) was found in non-walkers; no association was found in walkers.

Present treatment

No treatment had been offered to 82% (62/76) of the children with cold extremities, 48% (31/65) of the children with pain, 54% (29/54) of the children with sleeping disorders, and 31% (14/45) of the children with constipation. Those children, who had been treated, generally received orthopaedic technical aid such

as heating elements in socks for cold extremities and medications for pain, sleeping disorders and constipation.

General health

Ninety-three per cent (97.5/10) of the parents estimated the children's general health of both walkers and non-walkers to be good or very good.

Comments: Parents reported that 71% of the children had cold extremities. Cold extremities might be associated with sleeping disorders, constipation, pain, and impaired well-being. In most of the children, these symptoms had been present more than 1 year, but the symptoms were largely untreated.

Study IV.

Comparison of impact on mood, health, and daily living experiences of primary caregivers of walking and non-walking children with CP and provided community services support

Family characteristics

It was more common for the responders to live in two-parent families (74%) than in single parent families (28%). A two-parent family consisted of 2 adults, who lived in the family – even if 1 adult was not the biological parent of the child. Single parenthood was defined as the presence of a single adult in the family regardless of whether the parents were divorced, never married, or widowed. At the time of the study, 22% (23.5/106) of the children with CP were living with older siblings, 34% (36/106) with younger siblings, and 24% (25/106) with older and younger siblings; 20% (21.5/106) did not live with siblings.

Parental mood and health

Parents with non-walking children reported being anxiousness for their children's physical health more often than parents with walking children (Figure 3a). The proportion of anxious parents with non-walking children rose if their children had higher numbers of impairments and symptoms. A similar pattern also occurred when anxiousness for their children's psychological health was reported (Figure 3b).

Results

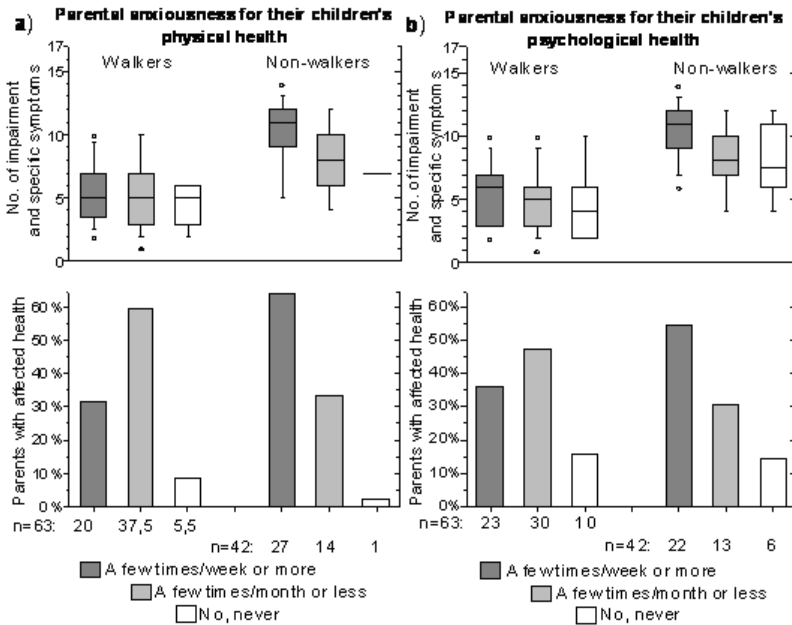


Figure 3. Proportion of parental anxiousness for walking and non-walking children's (a) physical and (b) psychological health and numbers of symptoms and impairments of the children by frequency of parental anxiousness; limits of the box show the 25th and 75th percentile, whiskers show the 5th and 95th percentile, circles indicate outliers

Fifty-eight percent of the parents stated that their health was affected due to their child's health. A larger proportion of parents with non-walkers were affected compared with parents with walkers, 75% and 47% respectively. The proportion of parents with affected health increased if anxiousness for their children's physical and psychological health was more frequent (Figure 4).

Results

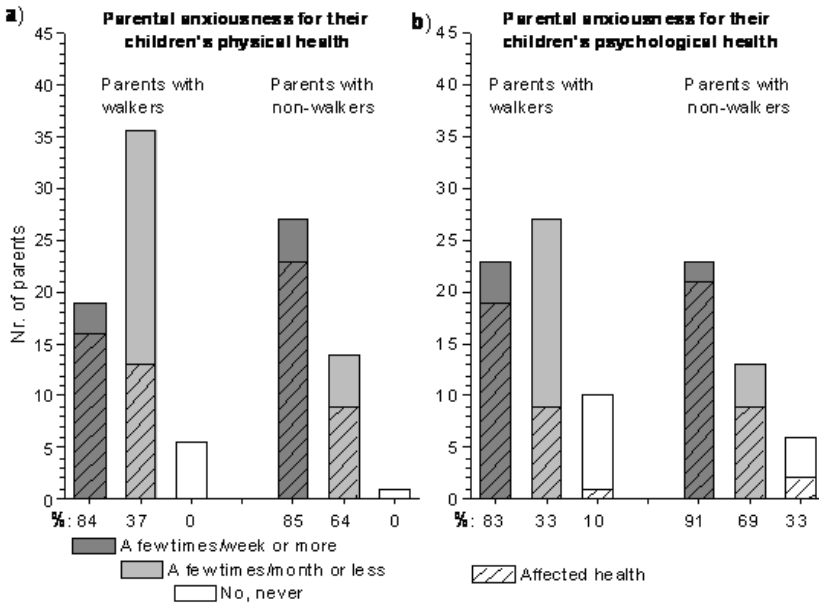


Figure 4. Numbers of parents with affected health by frequency of anxiousness for their walking and non-walking children's (a) physical and (b) psychological health; the bars' full height indicates numbers of anxious parents and the striped bars' height indicates numbers of parents with affected health; percentage under the bars represents the proportion of parents with affected health in the specific group

Of the children whose parents had affected health, a larger proportion had more symptoms (such as spasticity/dystonia, cold extremities, visual impairments, pain, sleeping disorders, impaired well-being, and constipation and were non-walkers) than children whose parents had unaffected health. Sleeping disorders, such as sleep onset latency, disrupted sleep, early awakening, circadian rhythm, or a combination of these, were commonly reported in non-walking children of parents whose health was affected.

Daily living experiences

Daily living interferences, such as restricted choice of family activities, interruptions of daily family activities, and cancelling or changing plans at the last minute, were reported more often by parents of non-walking children than parents with walking children.

Community services support

More than 50% of the families were supported by various community services such as personal assistance and short-term care. Community services support was more common for families with non-walking children than with walkers. The proportion of supported families with non-walking children rose if the children had higher numbers of impairments and symptoms. Ten families (10%), 5 with non-walkers and 5 with walkers, had no support but claimed that they needed it. Sixty-one per cent of the parents reported that their responsibility felt too heavy – compared to that taken on by community services support. This feeling was more frequent among parents with non-walking children – compared with parents with walking children, 84% and 45%, respectively.

Comments: Although many families cope well, care-giving for a child with CP may affect the parents' moods, health, and daily living – especially if the child has several impairments and symptoms. Frequent parental anxiousness regarding the child's physical and psychological health might be associated with affected parental health.

DISCUSSION

The thesis started with a pilot study to investigate whether acupuncture could increase skin temperature in 6 non-walking children with varying neurological disorders and cold feet. The result of clinical interest in this study was the tendency toward a cumulative effect in improved skin temperatures after supplementary acupuncture sessions. The pilot study also showed that the method was acceptable for all children. But the indication of acupuncture effects on skin temperature could not be generalized, because the study had a single subject design in which the child was its own control. At this point, further investigation in a larger group of children could have been the next step. But it was unknown if cold feet are a general symptom in children with neurological disorders and if the symptom is associated with the child's walking ability. Skin temperature was thus measured in children with and without neurological disorders – to objectively verify any temperature differences between the groups. This study showed that non-walking children with cerebral disorders had lower skin temperatures in both hands and feet than healthy children. Thus, the next study focused on children with cerebral palsy – to investigate if low skin temperature is associated with the child's walking ability or with other symptoms borne by the child. An association was found between cold extremities and pain, sleeping disorders, constipation, and impaired well-being. A higher frequency of these symptoms was reported in non-walking children than in walkers. Caring for these children with CP was found to affect the parents' mood, health, and daily living – especially if the child has several impairments and symptoms. Frequent parental anxiousness for the children's physical and psychological health seemed related to affected parental health.

Skin temperature

A symmetrical thermal pattern was shown in children with and without neurological disorders when comparing skin temperature in one side of the body to the corresponding opposite side (Study II). It is a normal finding in healthy subjects,⁶² but this was also shown in children with cerebral and spinal cord disorders. No correlation was seen between skin temperatures in hands and feet. The spatially organized sympathetic supply of the skin probably explained these results.⁸

Interestingly, healthy children were found to have lower skin temperatures in the feet than in the hands (Study II). Although, normal skin temperature is generally around 32°C.⁷ This is also in line with previous findings in healthy adults.⁶³

Skin temperature and central nervous system disorders

Lower skin temperatures in both hands and feet were found in non-walking children with cerebral disorders compared to healthy controls (Study II). Skin

temperature was also lower in the feet in children with cerebral disorders who were unable to walk compared to those who could walk. Not one child with spinal cord disorders was found to have cold extremities, although three out of four were non-walkers. Incomplete damage of the spinal cord in those children, or location of their lesions, probably explain absence of low skin temperature in the children with spinal cord disorders. The small sample size could also be the explanation for this observation and for the findings of higher skin temperatures in the feet in these children compared to healthy controls.

In an experimental study on 20 healthy adults, the standing posture was affected if the foot soles were cooled.⁶⁴ Whether or not posture of a child with severe motor disorders and cold feet will be further affected is unknown. But a cold extremity might be associated with an increased sensory threshold and an impaired tactile detection, which affect posture. Tactile sensory impairments have been found in the hands of 38 children with CP, classified at GMFCS level I and II.⁶⁵ So functional relevance of tactile deficits warrants further investigations.

Skin temperature may also affect nerve conduction measurements. Before measurements of nerve conduction velocity of the median and peroneal nerves, the limbs are recommended to be heated if skin temperature is less than 28°C of the dorsal side of the hand and less than 27°C of the dorsal side of the foot.⁶⁶ But at skin temperatures above 30°C, no relationship between skin temperature and motor nerve conduction is found. Hypothetically, in children with extremely low skin temperature in the extremities, the underlying motor nerve conduction might be impaired but its functional consequences are unexplored.

Skin temperature and sympathetic activity

At rest, there is a tonic discharge from sympathetic vasoconstrictor fibres, and vasodilatation results from a reduction in this basal tonic discharge.⁹ So in contrast to vessels that supply skeletal muscles, which have beta-receptors and sympathetic dilator control, skin vessels only dilate maximally when the sympathetic constrictor influence on them is eliminated. The hypothalamic temperature-regulating centre and afferent impulses to this centre from skin receptors particularly affect sympathetic nerves to the skin vessels.⁶ The hypothalamus also receives impulses from the frontal, motor, occipital, and temporal areas that serve to correlate somatic and autonomic functions. Altered activity in these cortical areas by stimuli, such as concentration, anxiety, discomfort or fright, will cause pronounced reflex changes in sympathetic vasoconstrictor tone and thus in the calibre of peripheral vessels.⁶

A decrease of the cortical and subcortical inhibitory effect on vasomotor neurons – which cause increased vasoconstriction and restricted cutaneous blood flow – might explain low skin temperature in stroke patients' affected extremities.⁴ Abnormal persistent vasoconstriction in stroke patients – due to a spinal reflex –

has also been suggested.³ The presence of sensory deficits, the side of the infarct, and the brain dominance were not related to the phenomenon.⁴ Disuse of a paretic limb has been suggested to affect vasomotor tone of the proximal parts of the limbs with large muscle groups but not the hands and feet with proportionately more skin and less muscle.³ So the low skin temperature seen in children with cerebral damages and severe motor deficit might be associated with increased sympathetic vasomotor tone due to damages in certain areas in the brain.

Little attention has been paid to the possibility of pathological sympathetic activity in children with cerebral palsy. As early as 1964, Ingram reported moderate-to-severe vasomotor changes in the limbs (measured by the back of the hand) in most of the 162 children with varying degrees of cerebral palsy.⁶⁷ In 1967, Holmes et al. found peripheral vasoconstrictive phenomena in 14 patients with cerebral palsy and observed a bilateral pedal vasodilatory response, warmer feet and increased dorsalis pedis and posterior tibialis pulses after surgical bilateral lumbar sympathectomy.⁶⁸ Electro-acupuncture in lower-legs (Study I) showed increased skin temperature in both hands and feet in some non-walking children with neurological disorders and cold feet. A plausible explanation for this effect might be a modulation of sympathetic activity at spinal and/or supraspinal level.⁶⁹ But Yang et al. did not find objective evidence of autonomic disturbances in 24 patients with cerebral palsy.⁷⁰ Children with severe quadriplegia were not enrolled in the study, and it was speculated as to whether the cortical area that mediates autonomic function might have been spared in the studied children.

Accompanying impairments and symptoms in CP

Disturbances of sensation, perception, cognition, communication, and behaviour; epilepsy; and secondary musculoskeletal problems often accompany motor disorders from cerebral palsy.²⁸ Besides the neurological impairments, we found that symptoms, such as cold extremities, pain, sleeping disorders, constipation, and impaired well-being were also reported in children with CP (Study III). The symptoms were more frequently reported in non-walking children with CP compared to walkers.

In stroke patients, an association was seen between clinical signs of pyramidal tract lesion and cold extremities, that is, the coldness was more pronounced in patients with severe paresis, spasticity, accelerated tendon reflexes, and extensor plantar response than in patients without those signs.⁴ Spasticity is a common symptom in children with cerebral lesions. But the role of spasticity in thermal dysfunction of the skin is doubtful, as the state of the underlying muscle, whether in sustained contraction or flaccid, is thought to have little influence on skin temperature.⁷¹ But many authors have noted a close relationship between pain and temperature decreases due to high levels of sympathetic vasoconstriction.⁷¹

Pain is common in children,^{38,72,73} adolescents⁷⁴⁻⁷⁶ and adults⁷⁷⁻⁷⁹ with CP. Liptak et al. reported significantly higher pain levels in children with CP – compared with the general population.⁷² Houlihan et al. found that 20.7% of parents of children with CP reported that their children had pain fairly often or every day.³⁸ Long-lasting, untreated pain may result in central sensitisation of nociceptive pain pathways and a chronic pain condition.⁸⁰ Adolescents with CP and persistent pain reported that communicating their pain was essential for effective treatment.⁷⁶ Many people with CP may not be able to verbally report their pain, which thus prevents them from receiving treatment.⁸¹ So clinicians must be familiar with a variety of pain assessments, including those that are appropriate for non-verbal individuals.⁸² A higher prevalence of sleep disturbances, which are frequently chronic, was also found in children with neurological and/or developmental disorders.⁸³ Chronic constipation is also a common complaint in children with severe brain damage.^{84,85}

Accompanying symptoms and sympathetic activity

An association between cold extremities and pain, sleeping disorders, constipation, and impaired well-being was noted in children with cerebral palsy (Study III). The question of why these symptoms are related remains. Decreased peripheral blood circulation – due to impaired motor ability – might cause low skin temperature. Pain could originate from muscles and joints or be a result of constipation and reflux. Difficulty in relaxing – combined with spasticity, anxiety, epilepsy or pain – may affect sleep. Constipation could be linked to immobility, medication, poor liquid intake, and use of pureed food. The child's perception of these symptoms might result in impaired well-being.

Cold extremities, pain, constipation, and sleeping disorders could also be linked to dysfunction of the autonomic nervous system in children with CP. Sympathetic fibres control skin blood flow in the hands and feet,⁸ and the relationship between pain and low skin temperature might be due to high tone in sympathetic vasoconstriction fibres.⁷¹ Chronic constipation in children with severe brain damage was found to result from prolonged transit through the more proximal segments of the colon.^{84,85} So impaired supraspinal coordinative influence on autonomic visceral nerves may result in intestinal dysfunction.

Sleep is a complex neurological function. Some researches suggest that the autonomic nervous system, which is involved in pineal melatonin secretion and sleep regulation, is affected in children with brain damage.⁸⁶ To fall asleep, the brain must inhibit the arousal state and the incoming excitatory stimuli: a process that is less efficient for many children with multiple disabilities. These brain waves originate from the thalamus, but they can only appear when the reticular formation is sufficient suppressed.⁸⁶

The autonomic nervous system function in children with CP is largely unexplored. But attempts have been made to investigate this area because several clinical symptoms in these children have been suggested to be a result of autonomic dysfunction. For example, 30 children with CP (aged 4–10) were age and gender matched with control subjects, and power spectrum analysis of heart rate variability (HRV) was used to investigate autonomic nervous system function.⁸⁷ A disturbed balance in the relative activity of the sympathetic and parasympathetic nervous system was observed for children with CP. It was suggested that disturbed modulating effects on autonomic function due to brain lesion in children with CP might account for presence of clinical dysautonomia such as bowel and bladder dysfunction, hyperhidrosis, and poor cardiopulmonary endurance.⁸⁷ Further, analysis of autonomic regulation using variational cardointervalography (VCIG) has shown dysadaptation in the compensatory cardiovascular system in 157 children with CP.⁸⁸ Severe adaptation was found in 73% of children with severe and very severe motor disorders and in only 32.8% with mild outcomes of CP.

Treatment

Presence of cold extremities, pain, constipation, and sleeping disorders in children with CP (Study III) indicate a need for greater attention to ongoing holistic management. The symptoms seemed to be accepted as inevitable consequences of the child's neurological impairment with treatment delays of more than 1 year for many of the children. Higher priority is probably given to other aspects of medical management such as treatment of motor function and postural deformity. Although motor disability is the hallmark of CP, physiotherapists should be aware that other concurrent conditions can confound the motor disorder and must be accounted for in the treatment.

Experimental and clinical studies suggest that afferent inputs in somatic nerve fibres have a significant effect on autonomic reflexes, pain, and visceral disorders.⁸⁹ Physiological counterparts can be seen in physical exercise, and the effect can be reproduced artificially via various types of electrical or manual stimulation to certain nerve fibres.¹³ Some disorders and disabilities may limit or prevent the children from performing certain types of physical exercises. So varying methods, such as acupuncture, which aim to activate sensory afferents may be provided as complementary or alternative treatment in these children. Acupuncture has a strong vasodilatory effect^{14,16,17,20} and affects pain control.¹³ Clinical experiences and clinical studies⁹⁰ suggest that acupuncture also may induce an increased sense of calmness and improved sleep in some patients. Other sensory stimulation methods are transcutaneous electrical nerve stimulation (TENS), vibratory stimulation, and massage – all induce excitation of receptors or nerve fibres in the stimulated tissue.¹³ But right now, inconsistencies exist in the literature regarding effects of

varying sensory stimulation techniques on peripheral blood flow and skin temperature in patients and healthy adults. And these inconsistencies demonstrate the importance of continuing work in this field.⁹¹⁻⁹⁵ Sensory stimulation effects are often investigated by occasional stimulations sessions, and more studies with a series of sessions with the same points and mode of stimulation are warranted.

In Study I, the onset, level, and site of temperature increase after acupuncture varied among the children. Similar results were seen when transcutaneous electrical stimulation of one extremity affected the temperature in other parts of the body in patients with peripheral ischaemia.⁹⁶ A delayed temperature increase was observed after stimulation of cold extremities. The increase had a latency of 15 to 30 mins. but was delayed even up to 240 mins. when the initial temperature was very low. Evaluation of heat treatment showed a correlation between the degree of vasodilation and the initial temperature, where vasodilation started in the warmest extremity.^{97,98} Once the reaction started, the amount of increase was the same in both warm and cold extremities. This possibly explains how the momentary effect in this study was primarily registered in the children's hands.

Of clinical interest in Study I was the possibility of extended effects on skin-temperature increases in two children after supplementary acupuncture sessions. One child experienced a temperature increase above the stated normal skin temperature of 32°C⁷ in the hands and toward 32°C in the feet at the end of the second series. But the other child did not experience temperature increases to normal skin temperature. The very low basal temperatures in the extremities – particularly in the feet – may have influenced the rate and extent of the response to acupuncture.⁹⁶⁻⁹⁸ One may speculate if additional acupuncture sessions and/or low frequency EA instead of manual stimulation of the needles should have extended the effect further.

In patients with xerostomia and Sjögren's Syndrome, repeat treatment with manual or low frequency EA resulted in an increase in the peripheral vascular flux.⁹⁹ Indications included an increase in the local blood flux that is more pronounced during a second course in patients who had previously reacted to acupuncture with increased saliva flow one to four yrs earlier. The results for the two children suggest that similar mechanisms might be activated in children with low peripheral skin temperature.

The child with Smith-Lemli-Opitz syndrome, who did not benefit from acupuncture, had a syndrome that can be associated with reduced nerve myelination, which might have reduced afferent stimulation effects.

The acupuncture treatment was acceptable to all children. It is important to have a calm, stress-free atmosphere during treatment. Findings of increased concentrations of cholecystokinin (CCK) in both animals and humans during anxiety and panic attacks^{100,101} support this idea. CCK is an endogenous opioid

antagonist and increased concentrations may reduce or completely negate positive effects of acupuncture treatment. It was probably very important that a person with whom the child felt secure was present throughout the treatment series and that the therapist was comfortable in the situation and well-known to the child.

Parental mood and health

Anxiousness for their children's physical and psychological health was reported more often by parents with non-walking children than by parents with walking children (Study IV). The proportion of anxious parents with non-walking children rose if their children had higher numbers of impairments and symptoms. The typical focus on studies is on reports of duration and intensity of varying symptoms of the child and seldom with a consideration for the impact these symptoms have on the child and the parents. But Houlihan et al. reported that parents of children aged 5–18, with severe motor impairment, CP, and high frequency of pain expressed more anxiety about their child's health and well-being than parents in the control population.³⁸ Brehaut et al. reported relationships between children's disabilities and caregivers' health.¹⁰² Phenomena that affect an individual family member are likely to affect other members of the family system. For example, if the child sleeps badly for a period of more than a year, it is likely to affect parent's health via chronic sleep interruption. Disturbances and curtailments of sleep might be a prospective risk for diseases due to changes in the endocrine, immune, and metabolic systems.¹⁰³ Unfortunately, sleeping disorders in children with CP are largely untreated, and many parents experience that short care relief is not available frequently enough. Improved sleep in the child should potentially have a beneficial impact on the parents' sleep and subsequent performance and health.

Most parents assessed their child's general health in more positive terms than the numbers of disabilities would suggest. As per the WHO, health is a state of complete physical, mental, and social well-being and not merely the absence of disease and infirmity.⁴¹ Accommodations for the child's disabilities might influence parental judgments of their children's general health – regardless of objective medical status or functional ability. But a high frequency of parental anxiousness for their children's physical and psychological health was associated with parental health.

Parental daily living experiences

More than 50% of parents with non-walkers frequently experienced restricted time for themselves and reported that family activities were often restricted and interrupted (Study IV). Parents of children with cognitive impairments have indicated that as their child's level of care increases, adequate time for themselves decreases.¹⁰⁴

Community services support and parental responsibility

Sixty-one per cent of the parents reported that their responsibility felt too heavy – compared to responsibility taken on by the community that provides services and support (Study IV). This feeling was more frequent for parents with non-walking children – compared to parents with walking children, 84% and 45%, respectively. Community services support might help the family situation and increase the family's ability to select the best way for them to live life with their child with CP. To determine service delivery needs, it will require consideration of accompanying impairments.¹⁰⁵ For example, respite services provide caregivers with a temporary break from their daily care-giving duties. Nearly half (46%) of 468 caregivers of children (aged 5-16) with cerebral palsy in Ontario reported using respite services in the past year.¹⁰⁶ Caregivers, who had a child with lower level of function (a higher GMFCS classification level) with multiple additional conditions, were more likely to use formal respite services. Most of these caregivers used more than one source of respite. The most common reason for using respite services was to get a break from caring for their child. Although more than 90% of caregivers indicated that respite use is beneficial for their family and the child, 60% reported facing many barriers while attempting to access respite services. The five most cited barriers were: respite resources were limited (for 50% of caregivers), respite was often difficult to arrange (47%), service the family needed was difficult to find (44%), caregivers were concerned about the quality of care the child would be receiving (29%), and information regarding respite services was difficult to find (11%). Caregivers, who had obtained support from community or social professionals or from health professionals, were more likely to have used respite services in the past years than those who had not.¹⁰⁶ Treneman et al. suggested that the severity of the child's disability places additional burdens on caregivers and therefore may lead them to seek respite care.¹⁰⁷ A possible alternative explanation for the relationship between the child's disability and caregiver's use of respite services may be that caregivers of children who have milder disorders would not qualify to receive services. Ten percent of the parents in Study IV reported that their need for services was unmet at the time. It is possible that their children, who had no learning disorders, were not qualified for help under LSS, but seeking help under SoL could have been another option.

Parents will probably have varying perceptions of what is necessary and adequate for them. So support programmes should be flexible enough to offer services that match families' actual needs. Regularly updated individual plans provide a platform for follow-up, evaluation, and future planning of adequate family support, for example.

METHODOLOGICAL CONSIDERATIONS

Sample size

The sample size in Study I was small. Only six children were included. However, this study was a pilot study to investigate if further studies would be worthwhile. Unfortunately, three of the children were not able to continue participating in the second series.

Only preschool children in Örnsköldsvik were considered in Study II – to make the population as comparable as possible and to minimize confounding factors of geographic and social character. All 17 children with cerebral and spinal cord disorders and 36 controls – with no signs of any central or peripheral nervous system disease – were invited to participate in Study II. Participation was 89% (15/17) and 69% (25/36), respectively.

The response rate in descriptive Studies III and IV was 68% (110 of 161). The number of responses may be influenced by factors such as whether the parents perceive it as relevant to provide the information. And whether non-responders were unable to interpret the questionnaire or simply chose not to reply. Because data from non-responding parents were unavailable – due to professional confidentiality – we do not know if information from the missing data would have varied from the respondent's data.

Skin temperature measurement

To avoid possible confounding factors that might affect skin temperature, the skin temperature measurements were always executed in the same room, which was thermostatically controlled. The children were also allowed to acclimatize to the room temperature for 20 minutes before measurements, and they did not have physical exercise before or during the equilibrium. No food was taken in 30 minutes before or during the measurements. All children were dressed in T-shirts and short pants in Study I. In Study II, all children were dressed but without socks.

Self-constructed questionnaire

It was not possible to find an instrument that fulfilled the purpose of Studies III and IV, so a self-constructed questionnaire was implemented. The questions were based on clinical knowledge and experiences, literature in similar areas, and personal communication with paediatric researchers. The instrument was pre-tested on two colleagues and three parents of children with neurological disorders (non-participants) and then revised as needed.

The purpose did not include parental illness, family stress, coping strategies, respondent education, age, or child behaviour problems – all of which might affect the results.

One of the most common generic tools available to assess impact of CP is the Child Health Questionnaire or CHQ⁵³, which evaluates health status and well-being of 5-18 year olds. Recently, in a review of the psychometric performance of the CHQ in samples of children with CP, some problems area were identified, and the authors concluded that further evaluative work (involving confirmatory factor analysis) must be done.¹⁰⁸ Until then, the authors recommend that researchers and clinicians exercise sensitivity during its administration and caution when interpreting results.

Proxy report

In Study III, data on the children's impairments and symptoms were collected by parental reports. Compared to an indirect assessment of a person by parents, family members, and caregivers, the assumption is that the child is the truest source of information.¹⁰⁹ But a low level of agreement between proxies and children is predominately seen when dealing with subjective dimensions – such as social and emotional functioning and psychological domains – compared with more observable aspects such as physical activity, functioning, and symptoms.¹⁰⁹ Further, it was important to obtain parental reports for all children – to include all children with CP, even those children who could not express themselves – to make comparisons of accompanying impairments and symptoms across the range of abilities. Despite obvious limitations and potential biases of proxy assessments, this report provides at least a partial view of the child's condition.

Gross motor function

The classification of gross motor function in children with CP via the GMFCS has enabled researcher and clinicians to determine the generalizability of research results. The distribution of gross motor function in Study III was rather similar to that reported by Himmelman et al., with 69% at GMFCS levels I–III and 31% at levels IV–V³⁷ and Howard et al., with 65% at GMFCS levels I–III and 34% at levels IV–V¹¹⁰, corresponding to 60% and 40% in Study III. But in studies by Nordmark et al.¹¹¹ and Beckung et al.,¹¹² the percentage of walking children with and without aid was larger, 73% and 70%, respectively. Walking ability varies strongly with CP type. Unilateral and ataxic CP types have the best walking ability and dyskinetic and bilateral CP types the least.¹¹² So differences between the studies in the distribution of walking ability might be due to local differences in distributions of CP types.

IMPLICATIONS AND FUTURE DIRECTIONS

Clinicians working with children with CP should be understand that these children have an increased risk for accompanying impairments and symptoms – besides their motor disability. Cold hands and feet might be one of these symptoms. So screening is needed, which should incorporate the multidimensional nature of CP, and the symptom must be detected and treated, if possible.

Clinicians must be familiar with a variety of pain assessments, including those that are appropriate for non-verbal individuals. An early identification of children at risk for pain would allow physiotherapists to contribute with valuable interventions that intend to prevent central sensitisation of pain and risk for a chronic pain condition.

Phenomena that affect an individual family member are likely to affect other members of the family system. So it is crucial to account for parents' need. Parental need covers a wide range of family life factors, and individual and holistic models of support are required. So professionals who work with these families should focus on *both* the family as a unit and on its individual members. Regular follow-up and evaluation of the child's treatment and family support are thus important.

In the future, it is important to (i) continue this work of investigating skin temperature disturbances in children with neurological disorders and their consequences and to (ii) find effective treatment methods.

Studies of special interest are:

- Investigation of skin temperature in a larger group of children with spinal cord disorders – to reveal whether or not these children have skin temperature disturbances.
- Investigations of autonomic function in children with neurological disorders.
- Sensory and pain thresholds and nerve conduction comparisons between healthy children with normal skin temperature and children with neurological disorders and cold extremities.
- Investigation of functional consequences of cold extremities.
- Intervention studies on sensory stimulation with the intention of modifying autonomic nervous-system activity in children with CP are warranted. In such studies, evaluation of effects on skin temperature *and* pain, constipation, sleeping disorders and well-being would be of interest. A simultaneous evaluation of effects on motor ability in such studies is also desirable. But finding a tool measuring small changes in motor ability in a child with severe motor impairment would be a real challenge.
- Mechanistic studies to investigate best mode, site, and duration of stimulation, and length and numbers of the treatment series to modify the autonomic nervous system activity.

Implications and future directions

Many varying factors are involved in how families with a disabled child are functioning. So expanding knowledge about parents' experiences as caregivers of children with CP is crucial. Studies of special interest are to:

- Investigate what exactly the parents are anxious about.
- Investigate how their health is affected.
- Describe measures that should be taken to limit the impact.

CONCLUDING REMARKS

Acupuncture may increase skin temperature in some children with neurological disorders and cold extremities.

Non-walking children with cerebral damage had significantly lower, mean hand and foot skin temperature compared to healthy controls.

Of the five symptoms – cold extremities, pain, sleeping disorders, constipation, and impaired well-being – most of the children with CP had had one or several symptoms for more than one year. Symptom frequency was generally higher in non-walking children than in walkers.

Of the children who had had symptoms for more than one year, a surprisingly large number had received no treatment for them.

Care-giving for a child with CP may affect the parents' moods, health, and daily living – especially if the child has several impairments and symptoms. Frequent parental anxiousness regarding the child's physical and psychological health might be associated to affected parental health.

Results of these studies, which are mainly of hypothesis-generating character, suggest that it is important to continue this work of investigating skin-temperature disturbance in children with neurological disorders – and its consequences – and to find effective treatment methods.

Results also show the importance of extending the knowledge about parents' experiences as caregivers of children with CP.

APPENDIX. Questionnaire

Barnet och familjen

1. Ditt barn/ungdom är en

- ☐ Flicka
- ☐ Pojke

2. Barnet är fött år

3. Var bor Ditt barn oftast?

- ☐ Med båda föräldrarna
- ☐ Hos ensamstående mamma
- ☐ Hos ensamstående pappa
- ☐ Hos mamma och en annan vuxen
- ☐ Hos pappa och en annan vuxen
- ☐ Växelsvis hos mamma och pappa
- ☐ I familjehem
- ☐ På elevhem

4. Bor Ditt barn vanligen tillsammans med andra barn?

- ☐ Ja, med yngre barn
- ☐ Ja, med äldre barn
- ☐ Ja, med både äldre och yngre barn
- ☐ Nej, inte med andra barn

Allmän medicinsk bakgrund

5. Bedömer Du att Ditt barn har en normal vikt i förhållande till sin längd?

- ☐ Ja
- ☐ Nej, låg vikt i förhållande till sin längd
- ☐ Nej, hög vikt i förhållande till sin längd

Ange gärna längd och vikt: cirka cm lång cirka kg i vikt

Appendix

6. Efter hur många graviditetsveckor är Ditt barn fött?

- ☐ 37 fullgångna veckor eller fler
- ☐ 32-36 veckor
- ☐ 28-31 veckor
- ☐ Färre än 28 veckor
- ☐ Vet inte

Ange gärna födelsevikt: cirka g

7. Vilka former av funktionsnedsättningar har Ditt barn?

	<u>Ja</u>	<u>Nej</u>
Rörelsehinder	<input type="checkbox"/>	<input type="checkbox"/>
Utvecklingsstörning	<input type="checkbox"/>	<input type="checkbox"/>
Talsvårigheter	<input type="checkbox"/>	<input type="checkbox"/>
Synnedsättning	<input type="checkbox"/>	<input type="checkbox"/>
Hörselnedsättning	<input type="checkbox"/>	<input type="checkbox"/>
Annan funktionsnedsättning	<input type="checkbox"/>	<input type="checkbox"/>
Beskriv gärna:		
.....		

8. Har Ditt barn några av följande svårigheter?

	<u>Ja</u>	<u>Nej</u>
Epilepsi (kramper)	<input type="checkbox"/>	<input type="checkbox"/>
Hög muskelspänning (spasticitet)	<input type="checkbox"/>	<input type="checkbox"/>
Växlande muskelspänning (tonusväxling eller atetos)	<input type="checkbox"/>	<input type="checkbox"/>
Inskränkt ledrörlighet (kontrakturer)	<input type="checkbox"/>	<input type="checkbox"/>
Svårigheter att äta	<input type="checkbox"/>	<input type="checkbox"/>
Svårigheter att dricka	<input type="checkbox"/>	<input type="checkbox"/>
Matproblem som medför matningsknapp på magen	<input type="checkbox"/>	<input type="checkbox"/>
Svåra andningsproblem	<input type="checkbox"/>	<input type="checkbox"/>
Kräkningar/sura uppstötningar (reflux)	<input type="checkbox"/>	<input type="checkbox"/>
Upprepade infektioner (mer än 1 gång per månad)	<input type="checkbox"/>	<input type="checkbox"/>
Urinläckage (inkontinens)	<input type="checkbox"/>	<input type="checkbox"/>
Hjärtproblem	<input type="checkbox"/>	<input type="checkbox"/>
Andra svårigheter	<input type="checkbox"/>	<input type="checkbox"/>
Beskriv gärna :		
.....		

9. Använder Ditt barn regelbundet någon av följande mediciner?

	<u>Ja</u>	<u>Nej</u>	<u>Vilka:</u>
Mediciner som minskar spasticitet	<input type="checkbox"/>	<input type="checkbox"/>
Mediciner mot epilepsi	<input type="checkbox"/>	<input type="checkbox"/>
Smärtstillande mediciner	<input type="checkbox"/>	<input type="checkbox"/>
Mediciner mot förstoppning	<input type="checkbox"/>	<input type="checkbox"/>
Andra mediciner	<input type="checkbox"/>	<input type="checkbox"/>
		

10. Vilken fysisk förmåga har Ditt barn?

Läs följande och **markera endast en** av de fem beskrivningarna som bäst motsvarar Ditt barns fysiska förmåga.

☐ Har svårigheter att sitta självständigt och att kontrollera huvud- och kroppsställning i de flesta positioner. Har begränsningar att uppnå någon viljemässig kontroll av rörelser. Behöver speciella stolar med extra stöd för att kunna sitta bekvämt. Behöver bli buren eller lyft med hjälpmedel vid förflyttning.

☐ Sitter självständigt men står och går med omfattande stöd. Är beroende av rullstol i hemmet, på skolan och ute i samhälle. Behöver ofta extra kropps- och/eller bålstöd för att underlätta arm- och handfunktion. Kan eventuellt uppnå självständig förflyttning med hjälp av elrullstol.

☐ Står utan stöd men går med hjälp av gånghjälpmedel (t.ex. med rollator, kryckor eller liknande). Har svårigheter att gå i trappor eller på ojämnt underlag. Kan behöva använda rullstol vid förflyttning långa sträckor eller i stora folksamlingar.

☐ Går självständigt utan gånghjälpmedel men behöver hålla i ledstången vid gång uppför eller nedför trappa. Har begränsningar att gå på ojämnt eller sluttande underlag och i folksamlingar.

☐ Går självständigt utan gånghjälpmedel och uppför eller nedför trappa utan att behöva hålla i ledstång. Går i alla omgivningar, även på ojämnt eller sluttande underlag och i folksamlingar. Kan springa och hoppa även om hastighet, balans och koordination (samordning av rörelser) kan vara något nedsatt.

Barnets hudtemperatur

11. Upplever Du att Ditt barn har kalla händer och/eller fötter?

- ☐ Ja, varje dag
- ☐ Ja, några gånger i veckan
- ☐ Ja, några gånger i månaden
- ☐ Ja, några gånger per år
- ☐ Nej, aldrig

Om Du svarat "Nej, aldrig" på fråga 11 gå vidare till fråga 22

12. När upplever Du att Ditt barn har kalla händer och/eller fötter?

- ☐ Både vid låg temperatur i omgivningen och i normal rumstemperatur
- ☐ Enbart vid låg temperatur i omgivningen

13. Vilken kroppsdel är kall på Ditt barn?

Kryssa för **alla** alternativ som stämmer

- ☐ En hand
- ☐ Båda händerna
- ☐ En fot
- ☐ Båda fötterna

14. Hur påtalar Ditt barn vanligtvis att händer och/eller fötter är kalla?

- ☐ Beskriver med ord
- ☐ Beskriver med tecken, bilder eller annan alternativ kommunikation
- ☐ Visar vilken kroppsdel som är kall t.ex med handen eller blicken
- ☐ Visar missnöje genom kroppsspråk eller ljud
- ☐ Påtalar det inte
- ☐ På annat sätt Beskriv gärna:.....
.....

15. Vad tror Du är orsaken till att Ditt barn har kalla händer och/eller fötter?

Kryssa för **alla** alternativ som stämmer

- ☐ Hög muskelspänning (spasticitet)
- ☐ Nedsatt rörelseförmåga
- ☐ Smärta
- ☐ Epilepsi
- ☐ Förstoppning
- ☐ Nedsatt blodcirkulation
- ☐ Annan orsak Beskriv gärna:

16. För hur lång tid sedan började Du notera kalla händer och/eller fötter hos Ditt barn?

- ☐ Mindre än 1 månad
- ☐ 1-5 månader
- ☐ 6-12 månader
- ☐ Mer än ett år

17. I vilken grad tror Du att kalla händer och/eller fötter påverkar Ditt barns

a. psykiska välbefinnande?

- ☐ Mycket
- ☐ Till viss del
- ☐ Inte alls

b. sömn?

- ☐ Mycket
- ☐ Till viss del
- ☐ Inte alls

c. rörelseförmåga?

- ☐ Mycket
- ☐ Till viss del
- ☐ Inte alls

18. Har Ditt barn fått någon hjälp mot kalla händer och/eller fötter?

- ☐ Ja
☐ Nej
-

Om Du svarat "Nej" på fråga 18 gå vidare till fråga 22

19. Vem tog initiativet till att hjälpa Ditt barn mot kalla händer och/eller fötter?

- ☐ Familjen själv
☐ Sjukvården Vilken verksamhet
☐ Annan Vilken person eller verksamhet.....

20. Vilken typ av hjälp mot kalla händer och/eller fötter har Ditt barn fått?

Kryssa för **alla** alternativ som stämmer

- ☐ Ortopedtekniskt hjälpmedel (t ex el-värmeslingor insydda i sockor eller el-värmesulor)
☐ Akupunktur
☐ TNS/TENS (svagströmsstimulering)
☐ Massage/taktil stimulering
☐ Värme (t ex bad eller värmedyna/värmekudde)
☐ Medicinering Vilken
☐ Extra varma kläder (t ex dunsockor)
☐ Annan åtgärd Beskriv gärna.....
.....

21. Är Du nöjd med effekten av åtgärderna?

	Mycket nöjd	Ganska nöjd	Ganska missnöjd	Mycket missnöjd
Ortopedtekniskt hjälpmedel	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Akupunktur	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
TNS/TENS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Massage/taktil stimulering	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Värme	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicinering	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Extra varma kläder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Annan åtgärd (enl fråga 20)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Barnets allmäntillstånd

Sömn

22. Upplever Du att Ditt barn har problem med sömnen?

- ☐ Ja, varje natt
- ☐ Ja, några gånger i veckan
- ☐ Ja, några gånger i månaden
- ☐ Ja, några gånger per år
- ☐ Nej, aldrig

Om Du svarat "Nej, aldrig" på fråga 22 gå direkt vidare till fråga 29

23. Hur visar sig Ditt barns sömnproblem?

	Varje natt	Några ggr i veckan	Några ggr i månaden	Några gång per år	Aldrig
Svårigheter att somna in	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vaknar ofta på natten	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vaknar tidigt på morgonen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Störd dygnsrytm	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

24. Vad tror Du är orsaken till barnets sömnproblem?

Kryssa för **alla** alternativ som stämmer

- ☐ Hög muskelspänning (spasticitet)
- ☐ Smärta
- ☐ Epilepsi
- ☐ Förstoppning
- ☐ Kalla händer och/eller fötter
- ☐ Känsломässig oro
- ☐ Annan orsak Beskriv gärna:.....

25. För hur lång tid sedan började Du notera sömnproblem hos Ditt barn?

- ☐ Mindre än en månad
- ☐ 1-5 månader
- ☐ 6-12 månader
- ☐ Mer än ett år sedan

Appendix

26. Har Ditt barn fått någon hjälp mot sitt sömnproblem?

- ☐ Ja
☐ Nej
-

Om Du svarat ”Nej” på fråga 26 gå vidare till fråga 29

27. Vilken form av hjälp har erbjudits Dig och Ditt barn för att påverka sömnproblemet?

Kryssa för **alla** alternativ som stämmer

- ☐ Muntligt stöd/Rådgivning
☐ Tekniska hjälpmedel (t ex speciellt anpassad säng/madrass)
☐ Medicinering till barnet Vilka:.....
☐ Annan åtgärd Beskriv gärna

28. Är Du nöjd med effekten av åtgärderna?

	Mycket nöjd	Ganska nöjd	Ganska missnöjd	Mycket missnöjd
Muntligt stöd/Rådgivning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tekniska hjälpmedel	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicinering till barnet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Annan åtgärd (enl fråga 27)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Välbefinnande

29. Upplever Du att Ditt barns psykiska välbefinnande är nedsatt?

- ☐ Ja, varje dag
☐ Ja, några gånger i veckan
☐ Ja, några gånger i månaden
☐ Ja, några gånger per år
☐ Nej, aldrig
-

Om Du svarat ”Nej, aldrig” på fråga 29 gå direkt vidare till fråga 32

30. Vad tror Du är orsaken till att Ditt barns psykiska välbefinnande är nedsatt?

Kryssa för **alla** alternativ som stämmer

- ☐ Hög muskelspänning (spasticitet)
- ☐ Smärta
- ☐ Epilepsi
- ☐ Förstoppning
- ☐ Kalla händer och/eller fötter
- ☐ Sömnproblem
- ☐ Annan orsak Beskriv gärna:.....

31. För hur lång tid sedan började Du notera nedsatt psykiskt välbefinnande hos Ditt barn?

- ☐ Mindre än en månad
 - ☐ 1-5 månader
 - ☐ 6-12 månader
 - ☐ Mer än ett år
-

Smärta

32. Upplever Du att Ditt barn har smärta?

- ☐ Ja, varje dag
- ☐ Ja, några gånger i veckan
- ☐ Ja, några gånger i månaden
- ☐ Ja, några gånger per år
- ☐ Nej, aldrig

Om Du svarat "Nej, aldrig" på fråga 32 gå direkt vidare till fråga 38

33. Vad tror Du är orsaken till Ditt barns smärta?

Kryssa för **alla** alternativ som stämmer

- ☐ Muskelsmärta
- ☐ Ledsmärta (t ex från höft)
- ☐ Epilepsi
- ☐ Förstoppning
- ☐ Kalla händer och/eller fötter
- ☐ Annan orsak Beskriv gärna:.....

34. För hur lång tid sedan började Du notera smärta hos Ditt barn?

- ☐ Mindre än en månad
- ☐ 1-5 månader
- ☐ 6-12 månader
- ☐ Mer än ett år

35. Har Ditt barn fått någon hjälp för att lindra smärtan?

- ☐ Ja
- ☐ Nej

Om Du svarat "Nej" på fråga 35 gå vidare till fråga 38

36. Vilken typ av hjälp har Ditt barn fått för att lindra smärtan?

Kryssa för **alla** alternativ som stämmer

- ☐ Muntligt stöd/Rådgivning
- ☐ Akupunktur
- ☐ TNS/TENS (svagströmsstimulering)
- ☐ Massage/taktil stimulering
- ☐ Värme (t ex bad eller värmedyna/värmekudde)
- ☐ Medicinering Vilka:.....

37. Är Du nöjd med effekten av åtgärderna?

	Mycket nöjd	Ganska nöjd	Ganska missnöjd	Mycket missnöjd
Muntligt stöd/Rådgivning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Akupunktur	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
TENS/TNS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Massage/taktil stimulering	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Värme	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicinering	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Förstoppning

38. Upplever Du att Ditt barn har förstoppning?

- ☐ Ja, varje dag
- ☐ Ja, några gånger i veckan
- ☐ Ja, några gånger i månaden
- ☐ Ja, några gånger per år
- ☐ Nej, aldrig

Om Du svarat "Nej, aldrig" på fråga 38 gå direkt vidare till fråga 44

39. Vad tror Du är orsaken till att Ditt barn är förstoppad?

Kryssa för **alla** alternativ som stämmer

- ☐ Nedsatt rörelseförmåga
- ☐ Känslomässig oro
- ☐ Äter finfördelad mat
- ☐ Litet vätskeintag
- ☐ Bieffekt av medicinering
- ☐ Annan orsak Beskriv gärna:

40. För hur lång tid sedan började Du notera förstoppning hos Ditt barn?

- ☐ Mindre än en månad
- ☐ 1-5 månader
- ☐ 6-12 månader
- ☐ Mer än ett år

41. Har Ditt barn fått någon hjälp mot förstoppningen?

- ☐ Ja
- ☐ Nej

Om Du svarat "Nej" på fråga 41 gå vidare till fråga 44

42. Vilken typ av hjälp har Ditt barn fått för att lindra förstoppningen?

Kryssa för **alla** alternativ som stämmer

- ☐ Muntligt stöd/Rådgivning
- ☐ Fysisk träning
- ☐ Medicinering Vilka:.....
- ☐ Annan åtgärd Beskriv gärna:

43. Är Du nöjd med effekten av åtgärderna?

	Mycket nöjd	Ganska nöjd	Ganska missnöjd	Mycket missnöjd
Muntligt stöd/Rådgivning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fysisk träning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicinering	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Annan åtgärd (enl fråga 42)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Generell hälsa

44. Hur har Ditt barns hälsa varit generellt sett under den senaste månaden?

- ☐ Mycket bra
- ☐ Ganska bra
- ☐ Ganska dålig
- ☐ Mycket dålig

Föräldrarnas situation och samhällsinsatser

45. Hur ofta är Du som förälder orolig för Ditt barns

a. fysiska hälsa?

- ☐ Varje dag
- ☐ Några gånger i veckan
- ☐ Några gånger i månaden
- ☐ Några gånger per år
- ☐ Aldrig

b. psykiska välbefinnande?

- ☐ Varje dag
- ☐ Några gånger i veckan
- ☐ Några gånger i månaden
- ☐ Några gånger per år
- ☐ Aldrig

46. Hur ofta har Du som förälder, under den senaste månaden, haft begränsad tid för Dig själv på grund av Ditt barns

a. fysiska hälsa?

- ☐ Varje dag
- ☐ Några gånger i veckan
- ☐ Vid något enstaka tillfälle
- ☐ Aldrig

b. psykiska välbefinnande?

- ☐ Varje dag
- ☐ Några gånger i veckan
- ☐ Vid något enstaka tillfälle
- ☐ Aldrig

47. Hur ofta, under den senaste månaden, har Ditt barns hälsa

a. begränsat familjens val av aktiviteter?

- ☐ Varje dag
- ☐ Några gånger i veckan
- ☐ Vid något enstaka tillfälle
- ☐ Aldrig

b. avbrutet vardagsaktiviteter i familjen (t ex under måltider och TV- tittande)?

- ☐ Varje dag
- ☐ Några gånger i veckan
- ☐ Vid något enstaka tillfälle
- ☐ Aldrig

c. orsakat inställda eller ändrade planer (personligt eller i arbetslivet) i sista minuten?

- ☐ Varje dag
- ☐ Några gånger i veckan
- ☐ Vid något enstaka tillfälle
- ☐ Aldrig

48. Har Din egen hälsa påverkats negativt på grund av Ditt barns hälsa?

- ☐ Ja
- ☐ Nej

49. Vilka av följande alternativ beskriver bäst den nuvarande arbetssituationen i familjen?

Kryssa för **alla** alternativ som stämmer

	<u>Kvinnan</u>	<u>Mannen</u>
Arbetar heltid som anställd eller i eget eller delägt företag	<input type="checkbox"/>	<input type="checkbox"/>
Arbetar deltid som anställd eller i eget eller delägt företag	<input type="checkbox"/>	<input type="checkbox"/>
Arbetar deltid på grund av mitt barns hälsa	<input type="checkbox"/>	<input type="checkbox"/>
Arbetar inte utanför hemmet	<input type="checkbox"/>	<input type="checkbox"/>
Arbetar inte utanför hemmet på grund av mitt barns hälsa	<input type="checkbox"/>	<input type="checkbox"/>
Personlig assistent till mitt barn	<input type="checkbox"/>	<input type="checkbox"/>
Sjukskriven i minst tre månader, sjukbidrag eller förtidspension	<input type="checkbox"/>	<input type="checkbox"/>
Föräldraledig	<input type="checkbox"/>	<input type="checkbox"/>
Studerande	<input type="checkbox"/>	<input type="checkbox"/>
Annan situation Beskriv gärna.....	<input type="checkbox"/>	<input type="checkbox"/>

50. Bedömer Du att familjens ekonomi är ungefär densamma som för andra familjer med jämförbar bostadssituation, arbete, antal barn, etc?

- ☐ Ja, ungefär densamma
- ☐ Nej, vår ekonomi är bättre
- ☐ Nej, vår ekonomi är sämre
- ☐ Vet inte

51. Har barnet och familjen tillgång till några av följande stödinsatser från samhället?

- ☐ Ja, personlig assistans av någon familjemedlem Timmar/vecka
- ☐ Ja, personlig assistans av utomstående person Timmar/vecka
- ☐ Ja, avlösarservice i hemmet Timmar/vecka
- ☐ Ja, särskilt korttidshem alternativt stödfamilj Dygn/månad
- ☐ Ja, ledsagarservice Timmar/vecka
- ☐ Ja, kontaktperson Timmar/vecka
- ☐ Ja, korttidstillsyn (t ex fritidshem) Timmar/vecka
- ☐ Nej, barnet/familjen har ingen av dessa men skulle behöva
- ☐ Nej, barnet/familjen har inget behov av dessa insatser

52. Hur ser Du på ansvarsfördelningen mellan föräldrar och samhälle för Ditt barn?

- ☐ Vi föräldrar måste ta för stort ansvar
- ☐ Vi föräldrar får ta lagom stort ansvar
- ☐ Vi föräldrar får ta för litet ansvar

53. Frågorna i enkäten har besvarats av

Kryssa för **alla** alternativ som stämmer

- ☐ Mamma
- ☐ Pappa
- ☐ Båda föräldrarna
- ☐ Mamma och annan vuxen
- ☐ Pappa och annan vuxen
- ☐ Tillsammans med barnet/ungdomen
- ☐ Annat alternativ

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